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Parental Understanding of Tuberous Sclerosis Complex

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Abstract

Tuberous sclerosis complex is a genetic disorder with multisystem involvement that poses significant challenges to the affected child and family. Caregiver knowledge in the South African population has not previously been reported. A prospective study of the parents of 21 children with tuberous sclerosis complex was undertaken. Median parental age was 38 (interquartile range 34.5-45) years. Parents were randomly allocated to receive written information about the condition, or to receive verbal counseling already established in clinic. A significant difference ($P = .001$) was observed in the change in the mean knowledge scores for the parent group that received written information (34.2 at baseline, 51.7 at the second visit. This impact was higher in parents with an education level of at least grade 8 ($P = .003$). Parental understanding of tuberous sclerosis complex can be improved by provision of written information and should be routinely available in a readily understandable format.

Keywords

tuberous sclerosis complex, tuberous sclerosis complex, seizures, autism, parental perceptions

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Tuberous sclerosis complex is a genetically inherited condition that manifests with benign noninvasive hamartomas in multiple organ systems, mainly skin, central nervous system, heart, kidneys, eyes, and lungs, resulting in varied clinical presentations. Prevalence of tuberous sclerosis complex in South Africa remains unknown.¹⁻³ Tuberous sclerosis complex can present in the neonatal period with seizures and occasionally cardiac compromise.¹ At least half of all patients with tuberous sclerosis complex have some degree of cognitive impairment.¹⁻⁵ Developmental, behavioral, and sleep disorders are common in tuberous sclerosis complex cohorts.⁶⁻⁹

Currently, tuberous sclerosis complex has no known cure. Active management of immediate problems with careful anticipatory evaluations for expected complications remains the mainstay of care with appropriate multidisciplinary input.¹⁰

Data on parental perceptions regarding tuberous sclerosis complex in their children remain limited.⁹ Parental and caregiver understanding of a child's chronic illness influences their ability to cope, their response to the child, and interaction with the health system.¹¹⁻¹⁵ Half of the parents of children with tuberous sclerosis complex are reported to have significant levels of psychological stress.⁹ Parents of children with more severe illness express lower satisfaction levels compared to parents of children needing fewer interventions.⁹⁻¹⁸ In the African context, the burden of social challenges such as stigma and disease are significant and contribute to the layering effects, which complicate provision

of optimal care.¹⁹ The term "layering" refers to the multiple issues prevalent in this setting inclusive of social challenges, poor nutrition, chronic coinfections, and limited access to basic health care, which in combination complicate both the assessment and ongoing management of these children.

Information relating to a child's chronic illness coupled with good communicative abilities of caregivers contribute to positive patient perceptions regarding illness and satisfaction with care provided.^{12,15} A caregiver's understanding of information provided regarding their child's illness has a significant impact on a child's health outcomes.²⁰⁻²³ Understanding of information provided is, in turn, partly dependent on one's literacy level.^{14-16,19} Recent systematic reviews point out benefits of provision of written information to parents along with care providers' personal inputs.^{24,25} Understanding of the disease demographics of tuberous sclerosis complex in Africa is

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lacking. This study sought to determine not only the level of understanding parents of children with tuberous sclerosis complex had but also whether provision of written material would be a useful adjunct to improvement of insight into the condition. Improvement in parental understanding of tuberous sclerosis complex has the potential to positively impact the care children with tuberous sclerosis complex receive.

Method

This prospective study aimed to describe parental understanding of tuberous sclerosis complex at Red Cross War Memorial Children's Hospital, Cape Town, South Africa. A dedicated tuberous sclerosis complex clinic at this facility is run by an accredited pediatric neurologist using internationally accepted guidelines.¹⁰ The diagnostic process involves informing the family of a clinically suspect diagnosis, followed by confirmation of the diagnosis of tuberous sclerosis complex. Confirmation of diagnosis is both clinical and neuroimaging based, according to fulfillment of the diagnostic criteria as genetic testing is not available in this setting.^{1,26} Parents are verbally counseled with regard to the nature of the condition, monitoring for complications, compliance with medications as required, and expected outcomes. Follow-up is typically between 3- and 6-monthly depending on the age of the child and his or her disease severity. At each consultation, open-ended questions are asked relating to patient progression and parental concerns. Supportive diagnostic and counseling services are available and utilized by this service.

One parent or caretaker (guardian) of each child with confirmed tuberous sclerosis complex was eligible for inclusion in the study. Parents who withheld their consent to participate in the study were excluded.

Baseline Parental Knowledge

Review of the literature failed to identify a suitable questionnaire that could be used to determine the baseline level of knowledge that parents had of tuberous sclerosis complex in children. A semistructured questionnaire was designed to determine parental understanding regarding tuberous sclerosis complex (see appendix). Responses to structured questions (quantitative analysis) were included in addition to some questions that were open ended (qualitative analysis). A score of 0 to 4 was allocated to responses given to the structured questions. A score of 0 was allocated for a wrong response whereas a score of 4 was allocated to a complete, correct response. This score was assigned after data collection and was not shown to the parents. A single rater blinded to the names of the patients during administration of the questionnaire recorded the precoded responses in all instances. Parents were given an opportunity to seek clarification regarding the questions.

All patients attending the tuberous sclerosis complex service were assigned a number from a table of random numbers. The patient group was then divided into two by random assignment. Parents of children in the first group received an information leaflet on tuberous sclerosis complex after the first visit, whereas parents in the second group received the information leaflet after the second visit. An adapted version of a parent information leaflet compiled by the tuberous sclerosis alliance²⁷ was used to provide information to parents. The information leaflet was translated into isiXhosa and Afrikaans, and then back-translated into English by another translator for accuracy.

Table 1. Comparison of Parental Background Characteristics.

Variable	Received leaflet (n = 11)	Did not receive leaflet (n = 10)	P value
Mean age, y	39.0	41.3	.41
Gender, n			.47
Female	10	8	
Male	1	2	
Marital status, n			.06
Married	5	9	
Not married	6	1	
Mean educational level of grade 8 (8 completed years of school), n	7	6	.28
Median duration of clinic attendance, mo	92	79	.62
Ancestry			.75
Mixed (African and European descent)	7	7	
African	4	3	

Recruitment into the study was undertaken during routine clinic visits. Written consent was undertaken once parents were fully informed of the study intention using Afrikaans or isiXhosa interpreters as needed. The questionnaire was administered for all those who gave consent. The information leaflet, in the preferred language, was provided to parents in the first group only.

Analysis of Understanding After Access to Written Material

During the second clinic visit, 3 months later, the questionnaire was administered again to parents in both groups. Any other sources of information accessed in the interim including the Internet, library books, and talking to other parents or medical professionals were recorded. Important knowledge gaps identified among the parents were addressed during the second clinic visit. The second group of parents received the information leaflet during the second clinic visit.

The Human Research Ethics Committee (University of Cape Town) reviewed and approved the study. HREC 270/2008.

Results

A total of 23 children attended the tuberous sclerosis complex clinic at Red Cross War Memorial Children's Hospital over a 6-month period and were approached to participate. Parents of 21 children gave consent to participate in the study; 18 parents or caregivers (85.7%) were female and 3 (14.3%) were male. The median parental age was 38 (interquartile range 34.5-45) years.

Parental characteristics are summarized in Table 1. Characteristics of children of the 21 parents included in this study are summarized in Table 2. None of the parents of children in this cohort were known to have tuberous sclerosis complex.

At entry into the study, the baseline parental level of knowledge was assessed. Thirteen (61.9%) parents knew that the name of the condition their child had was tuberous sclerosis complex, whereas 8 (38.1%) did not know the condition for

Table 2. Characteristics of 21 Children With Tuberous Sclerosis Complex.

Characteristic	Value
Median age, mo	137
Gender (male)	14 (67%)
Median duration of clinic attendance, mo	86
Median Developmental Quotient	74
Epilepsy	19 (90%)
Behavioral problem frequency	11 (52%)

which their child was on treatment. Two (9.5%) parents knew that tuberous sclerosis complex could be inherited and could also occur spontaneously, whereas 7 (33.3%) parents stated that tuberous sclerosis complex was an inherited condition. A total of 12 (57.1%) parents did not know the cause of tuberous sclerosis complex.

Twelve parents (57.1%) knew that a diagnosis of tuberous sclerosis complex was made by full clinical evaluation and investigations, whereas 4 (19.0%) parents thought that a diagnosis of tuberous sclerosis complex could be made by physical examination. Five (23.8%) parents did not know how a diagnosis of tuberous sclerosis complex was made.

Majority ($n = 13$, 62%) of the parents knew that brain magnetic resonance imaging (MRI) and computed tomographic (CT) scan of the head were helpful in making a diagnosis of tuberous sclerosis complex, and almost half ($n = 10$, 48%) indicated electroencephalography (EEG) was useful. None of the parents mentioned a Wood lamp examination of the skin.

Parental understanding of tuberous sclerosis complex manifestations was sought by asking them what organs or body systems were affected by tuberous sclerosis complex. Almost two-thirds of parents ($n = 13$, 62%) understood tuberous sclerosis complex affected multiple body systems, whereas 8 (38%) indicated that only the brain was involved.

Almost two-thirds ($n = 13$, 61.9%) of the parents understood that that tuberous sclerosis complex is not a curable condition, whereas 5 (23.8%) thought it was curable. Three (14.3%) parents did not know whether it was curable or not.

Regarding management, 5 (23.8%) parents responded that there was nothing that could be done to help children with tuberous sclerosis complex live better with their condition, whereas 6 (28.5%) parents stated that giving medication was of benefit to children with tuberous sclerosis complex. Three (14.3%) parents felt that either providing medications or visiting the doctor were adequate interventions for children with tuberous sclerosis complex. Seven parents (33.3%) knew that both medications and visiting the doctor to address the current problems and evaluate for new complications were suitable interventions.

All except 1 parent indicated that they considered seizures to be a possible complication of tuberous sclerosis complex. Majority ($n = 21$, 90%) of the patients had seizures attributable to tuberous sclerosis complex. Other complications of tuberous sclerosis complex identified by parents included behavioral problems ($n = 6$, 29%), learning difficulties ($n = 7$, 33%), and inability to participate in social activities ($n = 4$, 19%)

Table 3. Change in Parental Level of Knowledge Following Leaflet Administration.

Variable	Group of parents who received leaflet	Group of parents who did not receive leaflet	P value
Baseline mean score	34.2	39.2	.97
Second visit mean score	51.7	41.8	.02
Change in level of knowledge	20.1%	2.9%	.001

Table 4. Demographic Factors Associated With Level of Knowledge at Baseline and Second Stage of Study.

Variable	Association with initial score (P value)	Association with change in score (P value)
Parental age	.31	.95
Parental gender	.13	.52
Parental marital status	.71	.22
Parental ancestry	.92	.75
Duration of clinic attendance	.37	.63

Table 3 compares the recorded scores of parents who received the information leaflets with those of parents who did not. A mean knowledge score of 34.2 was recorded for this group prior to the administration of the information leaflet, and this increased to 51.7 after 3 months following access to the leaflet. For the second group, the mean knowledge score at the start of the study was 39.2 and 41.8 during the second visit. A statistically significant difference (P value = .001) was observed in the change in the level of knowledge on comparison between the parent group that received a leaflet and the group that did not during the second visit.

Exploration for association between the baseline level of knowledge and subsequent changes after provision of information with various demographic factors revealed no statistically significant associations. These findings are summarized in Table 4.

Analysis for significance in changes in the level of knowledge was performed for the group as a whole and also based on the mean educational levels for the group, which was 8 completed years of school. The impact of the information leaflet provided was greatest among parents who had completed at least 8 years of school as indicated by a statistically significant change in the level of knowledge (P value = .003). For those with a higher level of education (completed at least 11 years of school), the change in level of knowledge was less significant (P value = .025).

All parents cited the tuberous sclerosis complex service as their main source of knowledge regarding their child's illness. Four (19.0%) parents indicated having received additional information from other clinical services within and outside of Red Cross War Memorial Children's Hospital as well as from the Internet. The difference in baseline knowledge

Table 5. Issues Regarding Tuberous Sclerosis Complex That Were of Concern to Parents.

Issue of concern	First visit, n (%)	Mean baseline score	P value	Second visit, n (%)	Mean second score	P value
Severity of illness	4 (19.0)	39.2	.30	10 (47.6)	44.0	.34
An uncertain future	12 (57.1)	40.3	.82	18 (85.7)	48.6	.18
Effect of the child's illness on the family	4 (19.0)	32.7	.15	7 (33.3)	42.7	.44
Effect of the child's illness on me as a caregiver	0 (0)	0	0	3 (14.3)	32	.18
Cost of care/medication	0	0	0	0	0	0

score for parents who had access to additional sources of information had no statistically significant difference when compared to that of parents who had no other source of information (P value = .76).

During the second visit, 7 (33.3%) parents had obtained information from other sources, but the change in the level of knowledge in these parents compared to those who had no access to other sources of information on tuberous sclerosis complex was not statistically significant (P value = .24).

In response to a question that sought to establish the perceived extent to which parents felt tuberous sclerosis complex had affected the quality of their children's lives, 13 (61.9%) parents felt the condition had a significant negative impact on their child. Examples of negative impact stated included behavioral problems, school difficulties, developmental delay, and seizures. Three (14.3%) parents felt that tuberous sclerosis complex had a moderate negative impact on the quality of their children's lives, whereas 5 (23.8%) felt tuberous sclerosis complex had not had any effect on the quality of their children's lives. Parents of children most affected by tuberous sclerosis complex reported a greater negative impact.

The mean baseline knowledge score for the parents who felt tuberous sclerosis complex had a major negative effect on their children was 37.5 (standard deviation = 15.6), that of those who felt the effect was moderate was 29 (standard deviation = 14.0), whereas the mean score for those who felt tuberous sclerosis complex had had no effect was 41.2 (standard deviation = 21.2). The difference in the mean baseline knowledge scores of these 3 groups of parents was not statistically significant (P value = .61).

Table 5 summarizes the issues that were of greatest concern to parents of children with tuberous sclerosis complex. There were no statistically significant differences in the baseline level of knowledge and in the level of knowledge at the second visit on comparison between parents who raised a specific concern and those who did not.

Discussion

The statistically significant change in parental level of knowledge among those who received a leaflet were compared to those who did not, indicating that provision of easy-to-understand and ideally translated written information is a useful way of improving parental understanding of their child's condition.

The tuberous sclerosis complex clinic policy encourages open-ended verbal communication. Observed improvement in parental knowledge of tuberous sclerosis complex following provision of written information can partly be explained by circumventing cultural and language barriers that preclude adequate communication given the multiethnic nature of clinic attendants.²⁸

As illustrated in this study, a higher level of education equips one with better ability to understand written information and could also be a motivating factor for one to actually reading the information provided.¹⁴ Low literacy levels positively correlate with poor disease-specific knowledge.¹⁴⁻¹⁶ Strategies such as focused discussion group meetings can be advocated for groups with low literacy levels; these would be more supportive and could be viewed as less "threatening".

From this study, we can also infer that there is a greater need for education for those with less than eighth-grade education. The written information can help these individuals as well, but they could also need more of the verbal counseling in association with the written information.

It would be useful to note that this was a severely affected group of children; hence a significant negative impact of tuberous sclerosis complex on the quality of life for these children could have been a motivating factor for the parents, and could have contributed to the observed effect of the information leaflet. Similar studies on parental understanding report better insight among parents of more severely affected children.²⁹

The Red Cross War Memorial Children's Hospital service was the only source of information regarding tuberous sclerosis complex for majority of the parents interviewed. This fact highlights the importance of providing parents with adequate and ongoing, written information in addition to the clinical service.^{29,30} Previous studies have shown that patients attach great value to information given by their health providers regarding their condition.^{12,24,25} In this particular study, access to other forms of information had no significant impact. This finding underscores the value of targeted, appropriately translated information from the care provider.

Interestingly, duration of attendance at the clinic had no association with the level of knowledge a parent had at the beginning of the study. Causes for this observation are likely multifactorial, ranging from inadequate parental motivation and social factors including different relatives, attending clinic with the child, which is common in Africa. Additionally, this

observation could reflect lack of additional education and reinforcement of understanding of tuberous sclerosis complex beyond the initial counseling. This could easily occur in a tuberous sclerosis complex clinic where the focus of care remains management of chronic problems and anticipatory assessment for known complications. Previous studies have demonstrated that patients' need for education regarding their condition does not correlate to the duration for which they have had their condition.^{12,13,28} This would be particularly important in the African context, where general public awareness regarding diagnosis and potential improvement of outcomes for chronic conditions through appropriate care is minimal.^{30,31}

Based on the findings in the study at commencement of the project, the diagnosis of their child's condition, as well as the cause of tuberous sclerosis complex, was not as well understood by a significant proportion of the parents despite the counseling they had initially received and the opportunity to gain further information during any of the return clinic visits. These observations were probably due to the fact that these were particularly difficult concepts for nonmedically trained people to understand. It has been observed previously that the complexity of a clinical concept can influence the patient's ability to understand facts presented though this can also be influenced by the health provider's communication skills, culturally conceived ideas, and language barriers.¹⁴

A majority of the parents understood that brain MRI and EEG are useful tests for children with tuberous sclerosis complex. This is most probably explained by their own experience with the investigation process as indicated by no responses regarding the Wood lamp assessment, which is a less commonly used investigation tool. A good understanding of both the investigation and medication processes contributes positively to adherence and compliance.²⁰⁻²³

One-fifth of the parents interviewed felt that there was not much that could be done for patients with tuberous sclerosis complex. This perception was probably due to the observed chronicity of the condition and persistence of complications in their own children. A statistically significant association between the parental level of knowledge with parental observation of the impact of tuberous sclerosis complex on their child's life was not elicited in this study, though parents of more severely affected children reported a greater negative impact. Rodenburg et al¹¹ and Morrow et al¹⁸ have also shown that parental perception of a child's illness closely correlated with the actual severity of the child's illness.

Conclusion

Parental understanding of tuberous sclerosis complex can be improved by provision of appropriate written information, especially for those who have completed at least 8 years of schooling. Ongoing education needs to be provided throughout the duration of contact with the tuberous sclerosis complex service to enhance parental understanding of tuberous sclerosis complex and possibly that of other chronic illnesses.

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Author Contributions

PS devised the study protocol and undertook the study, which formed part of her MPhil thesis (Characteristics of Tuberous Sclerosis Complex in a South African Cohort: Description and Parental Understanding) completed in 2010. BS assisted in recruitment of the study group and provided information on the children. KD characterized specific clinical aspects and provided input to the manuscript. JW supervised the study and provided input to the manuscript.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Ethical Approval

The Human Research Ethics Committee (University of Cape Town) reviewed and approved the study (HREC 270/2008).

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